

# A longitudinal qualitative exploration of healthcare and informal support needs among survivors of critical illness: the RELINQUISH protocol

Pam Ramsay,<sup>1</sup> Guro Huby,<sup>2</sup> Janice Rattray,<sup>3</sup> Lisa G Salisbury,<sup>2</sup> Timothy Simon Walsh,<sup>4</sup> Susanne Kean<sup>2</sup>

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<sup>1</sup>Department of Anaesthesia and Critical Care (Research), Royal Infirmary of Edinburgh, Edinburgh, UK

<sup>2</sup>School of Health in Social Science, University of Edinburgh, Edinburgh, UK

<sup>3</sup>School of Nursing and Midwifery, University of Dundee, Dundee, UK

<sup>4</sup>Critical Care Medicine, Centre for Inflammation Research, Edinburgh University, Edinburgh, UK

**Correspondence to**  
Dr Pam Ramsay;  
[pam.ramsay@ed.ac.uk](mailto:pam.ramsay@ed.ac.uk)

## ABSTRACT

**Introduction and background:** Survival following critical illness is associated with a significant burden of physical, emotional and psychosocial morbidity. Recovery can be protracted and incomplete, with important and sustained effects upon everyday life, including family life, social participation and return to work. In stark contrast with other critically ill patient groups (eg, those following cardiothoracic surgery), there are comparatively few interventional studies of rehabilitation among the general intensive care unit patient population. This paper outlines the protocol for a sub study of the RECOVER study: a randomised controlled trial evaluating a complex intervention of enhanced ward-based rehabilitation for patients following discharge from intensive care.

**Methods and analysis:** The RELINQUISH study is a nested longitudinal, qualitative study of family support and perceived healthcare needs among RECOVER participants at key stages of the recovery process and at up to 1 year following hospital discharge. Its central premise is that recovery is a dynamic process wherein patients' needs evolve over time. RELINQUISH is novel in that we will incorporate two parallel strategies into our data analysis: (1) a pragmatic health services-oriented approach, using an a priori analytical construct, the 'Timing it Right' framework and (2) a constructivist grounded theory approach which allows the emergence of new themes and theoretical understandings from the data. We will subsequently use Qualitative Health Needs Assessment methodology to inform the development of timely and responsive healthcare interventions throughout the recovery process.

**Ethics and dissemination:** The protocol has been approved by the Lothian Research Ethics Committee (protocol number HSRU011). The study has been added to the UK Clinical Research Network Database (study ID. 9986). The authors will disseminate the findings in peer reviewed publications and to relevant critical care stakeholder groups.

## ARTICLE SUMMARY

### Article focus

- This is a nested, qualitative longitudinal study of informal support and healthcare needs among participants in a randomised controlled complex rehabilitative intervention for survivors of critical illness (the RECOVER study).
- Its central premise is that recovery is a dynamic process wherein patients' needs evolve over time.
- This study will explore patient experience and will identify specific needs at key points in the recovery process, for the purpose of developing timely healthcare interventions.

### Key messages

- Qualitative studies of recovery are comparatively rare among survivors of critical illness, and longitudinal studies are rarer still.
- Qualitative approaches provide rich and detailed insights into patient experience that are often inaccessible by questionnaire based approaches (alone).

### Strengths and limitations of this study

- A key strength of this study is its analytical strategy. Methodological triangulation with the 'parent' study's quantitative outcome data will enhance its interpretation. Theoretical triangulation will (1) produce pragmatic data for the purposes of health services development and (2) enhance theoretical understandings of the recovery process.
- A potential limitation, however, is the resource intensity of the analytical process.

## INTRODUCTION

Until comparatively recently, short-term survival (ie, intensive care unit (ICU), hospital or the 28-day all-cause mortality commonly reported in clinical trials) was considered the primary end point in critical care interventional studies. It is increasingly recognised, however, that survival is

associated with a broad spectrum of physical and psychosocial sequelae<sup>1–6</sup> with often refractory effects upon health-related quality of life (HRQoL).<sup>7–10</sup> Common physical morbidity includes muscle wasting, weakness, fatigue, weight loss, joint stiffness and breathlessness on exertion.<sup>1</sup> Survivors report impairment in mobility and the performance of everyday activities for many months and sometimes years following hospital discharge.<sup>2 3 11</sup>

An increased prevalence of anxiety, depression and post-traumatic stress disorder (characterised by distressing and intrusive 'flashbacks') has been reported<sup>4 5</sup> and is associated with poorer functional outcomes,<sup>12</sup> the protraction of the recovery process<sup>13</sup> and reduced social participation.<sup>14</sup> Cognitive deficits in memory, concentration and executive function (eg, decision making) are also prevalent,<sup>5 6</sup> often interfering with the ability to perform everyday activities<sup>6</sup> (eg, managing money, shopping, etc) and return to work.<sup>13</sup>

An impressive corpus of literature has described decrements in health status and their recovery over time using standardised HRQoL questionnaires. Comparatively little is known, however, about the significance or effects of prevalent morbidity (eg, weakness and fatigue) in survivors' *everyday lives*. The little that is currently known has been extrapolated from qualitative studies among other patient populations (eg, stroke and cancer), from clinicians involved in critical care outreach or follow-up services or from longitudinal critical care studies, which engage with participants *face to face*. Herridge *et al*'s work among survivors of adult respiratory distress syndrome is particularly notable,<sup>2 3</sup> prompting calls to abandon a 'compartmentalised view of critical illness' and to adopt instead the notion of a continuum which includes pre-existing illness, the critical illness episode and survivors' physical and psychosocial rehabilitative needs.<sup>15</sup>

This 'continuum' should sensibly include (1) recent work on transitions of care across healthcare settings among patient populations with complex needs<sup>16–18</sup> and (2) contemporary conceptualisations of recovery which focus upon intrapersonal and psychosocial adaptation as opposed to the mere resolution of symptoms or improvement in functional status.<sup>19</sup> The following sections outline the breadth and complexity of the issues.

### The critical care continuum

#### Pre-existing health status has important effects upon processes of care and recovery

Comorbidity is of particular importance in critical care research, given its increased prevalence among ICU patient populations<sup>20</sup> and current demographic trends. Poor HRQoL among survivors is more strongly associated with previously poor HRQoL or prior chronic illness than with illness severity scores on ICU admission.<sup>9 20</sup> Comorbidity has been associated with acute hospital length of stay<sup>21</sup> and has implications for the

fragmentation of care, given the increasing emphasis upon specialisation in healthcare.<sup>22</sup> Synergistic effects may also exist between prevalent chronic and age-related disorders (eg, cardiovascular and chronic respiratory disease) such that patients may experience an increased risk of physical impairment,<sup>23</sup> poorer rehabilitative outcomes<sup>24</sup> and reduced HRQoL<sup>25</sup> than might reasonably be expected from their separate effects.

The relationship between comorbidity and outcomes has been explored using, almost exclusively, standardised indices of comorbidity and health status instruments. Very little is known about the cumulative effects of pre-existing health status and critical illness-related morbidity in the *everyday lives* of survivors or about the significance and effects of intrapersonal and psychosocial adaptation associated with pre-existing or chronic illness. Research among the chronically ill suggests, for example, that notions such as resilience<sup>26</sup> and self-efficacy<sup>27</sup> may, in fact, attenuate poor perceived health status in the face of debilitating or life-threatening illness.<sup>28 29</sup> This work has received remarkably little attention in the critical illness literatures. Although not a primary feature of this research, we will attempt to explore these phenomena in the RELINQUISH study.

#### The ICU experience

Amnesia, dreams (of an often persecutory nature) and delusional memories are extremely common and may constrain survivors' ability to 'piece together' the events surrounding ICU admission, the chronology of clinical events or indeed to develop a realistic appreciation of illness severity.<sup>30</sup> Dreams and delusional memories can be more vivid and emotive than the recall of factual events (eg, care or treatment-related activities) or bodily sensations (eg, thirst, discomfort) and have been consistently associated with anxiety, depression and post-traumatic stress symptomatology.<sup>4 31 32</sup> Unlike other illnesses with a common cultural paradigm and/or a more insidious onset (eg, rheumatoid arthritis), the frequently emergency, opportunistic or inexplicable nature of critical illness may deny survivors a tangible basis upon which to attribute meaning or causality.<sup>30</sup>

#### Ward-based care and rehabilitation can have important effects upon recovery

ICU survivors are at increased risk of deterioration or serious adverse events following discharge to the general wards.<sup>33</sup> ICU outreach or liaison nurse roles have been widely adopted elsewhere in the UK as part of a service-wide approach to critical care. In the absence of centralised funding, there is little such provision in Scotland, with potential implications for this patient group. Survivors are dispersed widely throughout the acute hospital setting, and ward-based staff may have limited recognisance of the broad spectrum of early critical illness-related morbidity (see online appendix 1). They may also be poorly equipped in terms of resource, knowledge and clinical skills to manage the acuity or complexity of this patient group.<sup>34 35</sup>

ICU survivors frequently suffer from profound weakness, generalised muscle wasting, impaired mobility and weight loss on transfer to the general ward, a situation described as 'inexplicable and worrying'<sup>36</sup> and a 'critical defining characteristic' of the distress survivors experience at this time.<sup>37</sup> These patients are often highly dependent. Recent qualitative research suggests that they may receive inadequate levels of care, which are attributed to low levels of staffing and a perceived lack of understanding or indifference among hard-pressed nursing staff to their basic care needs, with, importantly, deleterious effects upon short-term recovery.<sup>30 38</sup>

Qualitative research among stroke populations suggests that while patients perceive physiotherapy to be central to the recovery process,<sup>39 40</sup> many are dissatisfied with its frequency, intensity and brevity and the extent of recovery at hospital discharge.<sup>40</sup> Indeed, our local service evaluation revealed that patients practiced mobility treatments (ie, transfers and walking) with physiotherapists only once per week.<sup>41</sup> Our local qualitative research also suggests that survivors' informational needs with regard to the likelihood and aetiology of ICU-acquired weakness, self-management strategies and the extent and likely time course of the recovery process following discharge home were rarely met.<sup>30</sup>

### Post-hospital discharge experiences

Patients are rarely able to anticipate and/or articulate their own post-discharge needs<sup>30</sup> and while many perceive discharge home as the start of a 'proper' recovery,<sup>42</sup> the transition between hospital and home is often unexpectedly difficult.<sup>30</sup> A number of factors have been implicated in suboptimal post-discharge outcomes. These include failure to develop comprehensive discharge plans due to time and resource constraints,<sup>43 44</sup> failure to recognise the complexity of patients' needs,<sup>45</sup> poor communication within the multidisciplinary team in the acute hospital setting,<sup>46</sup> with patients and family members<sup>47 48</sup> and with clinicians in the community setting.<sup>49</sup>

ICU survivors in our local qualitative research reported significant and unanticipated difficulties in their everyday lives following discharge home and were highly dependent upon close family members, often as a result of inadequate rehabilitative input, inadequate discharge planning, unrealistic expectations of recovery, ongoing morbidity and variability in access to community-based support.<sup>30</sup> Qualitative work among participants in a UK ICU follow-up service revealed that patients' psychosocial needs were rarely addressed during the acute hospital stay.<sup>50</sup> Participants valued continuity of care; additional monitoring and expedited referral; the receipt of information on the admitting illness, the chronicity of treatments and events; and the opportunity to ask questions and expert reassurance. They also valued the timely organisation of follow-on (ie, community based) support but noted, importantly, a lack of knowledge among general practitioners with regard to their critical illness.<sup>50</sup> In the absence of ICU

follow-up services, these needs are likely to remain unmet.

### Social support

In the absence of a dedicated rehabilitative pathway<sup>33</sup> and burgeoning policy initiatives towards early acute hospital discharge, survivors may be discharged home 'sicker and quicker'. Family members therefore often shoulder significant care responsibilities following hospital discharge, making important lifestyle changes (eg, balancing family, work and leisure activities) for which many are unprepared.<sup>51 52</sup> Recent qualitative work among the critically ill describes family support as central to recovery; participants, for example, emphasised that "had they not had family to depend on, they might have taken longer to recover, not recovered so well or not recovered at all."<sup>50</sup>

Perceived social support may be associated with a decrease in psychosocial problems among survivors of critical illness,<sup>53</sup> although the processes through which this might occur are not currently understood. Indeed, remarkably little is known about the nature and scope of ICU survivors' support needs following discharge home due, potentially, to the perspective that social support is beyond the remit of medical intervention.<sup>54</sup> They are likely to be significant, however, given the physical and psychological sequelae of critical illness and the effects of shortfalls in the processes of care previously described.

### Interventional studies of rehabilitation are rare

Data from other patient populations (eg, stroke) consistently demonstrate that patients derive significant and sustained benefit from organised multidisciplinary rehabilitation in the acute healthcare setting.<sup>55</sup> In contrast to other critically ill patient groups (eg, following cardiac surgery), integrated rehabilitative pathways do not currently exist.<sup>33</sup> The National Institute for Health and Clinical Excellence, however, recently developed guidelines for rehabilitation specific to the general ICU patient population (National Institute for Health and Clinical Excellence, 2009).<sup>33</sup> Due to the limited available evidence upon which to base their recommendations, the guidelines are based upon expert opinion and consensus. Interventional studies of rehabilitation are nonetheless beginning to emerge among the critical care community. The RELINQUISH study, as previously described, is a nested longitudinal qualitative study of family support and perceived healthcare needs among one such study.

### The 'parent' study: RECOVER

The RECOVER study is described elsewhere in this journal in detail.<sup>56</sup> RECOVER is based upon extensive literature review and completed local research comprising: a prospective audit of physiotherapy and dietetic intervention between ICU and hospital discharge,<sup>41</sup> a qualitative study exploring quality of life among survivors of prolonged critical illness<sup>30</sup> and

a feasibility randomised controlled trial of enhanced physiotherapy and dietetic management using a dedicated rehabilitative assistant.<sup>57</sup>

Participants in the RECOVER study (n=240) will be randomised into one of the two groups. The control group will receive standard rehabilitation and the intervention group will receive enhanced rehabilitation delivered by the rehabilitation assistant, under the supervision of existing ward-based multidisciplinary teams. The primary outcome measure is functional disability at 3 months following hospital discharge. Secondary measures include muscle strength, 2 m timed up and go,<sup>58</sup> nutritional status, visual analogue scales for fatigue, appetite, breathlessness, joint stiffness and pain, HRQoL, psychological morbidity and satisfaction. RECOVER also incorporates a health economic (cost-effectiveness) evaluation.

Given the potential insensitivity of quantitative measures to processes of implementation and change,<sup>59</sup> RECOVER incorporates a mixed methods evaluation, comprising focus groups with (1) key healthcare professionals in the acute setting and (2) participants and family members from the standard care and enhanced rehabilitation groups. Qualitative evaluation among the former will explore barriers to and successful strategies in the implementation of the intervention, including the 'acceptability' of the generic assistant as a novel strategy for rehabilitative provision. Qualitative evaluation among survivors and family members will explore and compare experiences of recovery and rehabilitation up to 3 months following ICU discharge in relation to key issues and concerns.

### RELINQUISH: AIMS AND OBJECTIVES

We will explore family support and perceived healthcare needs at key stages in the critical care 'continuum'; their evolution over time; assess the extent to which they are currently met by informal and professional community-based resources and identify potential service improvements throughout the recovery process. We will also explore the effects of the RECOVER intervention upon the perceived healthcare and support needs of survivors following discharge into the community.

### METHODS AND ANALYSIS

#### Participants

Inclusion criteria are those of the RECOVER study, namely that participants required ≥48 h of continuous invasive (via an endotracheal and/or tracheostomy tube) mechanical ventilation in the ICU. Exclusion criteria comprise a primary neurological admission diagnosis (brain trauma, intracerebral bleed, stroke, Guillain–Barre syndrome); provision of palliative care; patients for whom a dedicated rehabilitation programme already exists (eg, transplantation, stroke, post-cardiac surgery); patients currently receiving or referred for home ventilation; patients discharged from ICU to a non-study hospital where the intervention cannot be

received; the follow-up visit at 3 months is not feasible for geographical reasons; communication difficulties (eg, language), the patient is enrolled in another randomised controlled trial with similar end points or is aged <18 years at the time of screening.

#### Sampling strategy

In order to explore the family support and perceived healthcare needs among relevant subgroups of the patient population, we will purposively sample 12 patients from both the 'standard care' and 'enhanced rehabilitation' arms of the RECOVER study according to pre-defined criteria. These comprise: age (relevant in relation to employment status), gender (relevant in terms of post-hospital discharge care giving or support activities), duration of mechanical ventilation (relevant in terms of the prevalence and severity of critical illness-related morbidity), the presence of significant pre-existing comorbidity (relevant in terms of prior strategies and resources to support recovery) and social support.

#### Data collection

Participants will be approached for consent during the general ward phase of recovery. We will interview participants (a) just prior to acute hospital discharge (b) 4–6 weeks after hospital discharge (c) 6 months after hospital discharge and (d) 1 year after hospital discharge. The first interview will take place in the acute hospital setting and the remainder will be conducted, preferably, in participants' homes. Time points (a) and (b) have been selected on the basis of previous local qualitative research<sup>30</sup> and will explore and compare processes of care between both groups, including their impact upon 'anticipated' and 'actual' support and healthcare needs early post-discharge. Time points (c) and (d) coincide with those of the 'parent' study and with the existing literature.

We will invite participants to describe their experiences of and perspectives on family support and interactions with healthcare professionals throughout the acute hospital, community and outpatient settings and to describe the extent to which their perceived needs were met. The interview schedules have been constructed on the basis of previous local qualitative research,<sup>30</sup> extensive literature review and around key elements of the RECOVER intervention, examples of which are provided in online appendices 2–4.

#### Data analysis

Data collection and analysis will proceed iteratively. With participants' consent, the interviews will be recorded via a digital voice recorder and transcribed verbatim. All data will be anonymised and coded using computerised qualitative data analysis software (NVIVO 8®). The data will be analysed in accordance with the sampling criteria previously described. We will also compare the questionnaire-based data of the 'parent' study with our interview data at 6 and 12 months ('methodological

triangulation') for the purposes of enhancing analysis (see online appendix 5).

More importantly, we will incorporate 'theoretical triangulation' into our analytical strategy for the purpose of decreasing, negating or counterbalancing the potential deficiencies of a single analytical perspective and to enhance interpretation of the data<sup>60</sup> (see online appendix 5). One researcher will use the 'Timing It Right' (TIR) framework,<sup>61</sup> whereas the other will use a constructivist grounded theory approach. The researchers will analyse the data independently and produce reports of their own determination of themes, subthemes and issues both within and across the four stages of data collection for discussion at regular team meetings.

#### Approach 1: TIR framework

It is increasingly recognised that patients' healthcare and support needs evolve throughout the illness (and indeed recovery) trajectory.<sup>16–18 61 62</sup> Originally developed for use among family members of stroke survivors, TIR provides a useful framework within which to explore survivors' needs throughout the critical care continuum (the critical illness event, ward-based rehabilitative provision and the return to community living) by describing four key support needs: informational, emotional, instrumental (support in relation to activities of daily living) and appraisal (external feedback or reassurance)<sup>60</sup> (online appendix 6).

Its recent use among survivors of critical illness<sup>62</sup> suggests that prior to hospital discharge, informational needs were related to community services, return to work and access to social services. Concerns during early adjustment to life at home included physical and emotional dependence upon informal care givers (emotional and instrumental needs) and the desire for more 'tangible' professional support such as additional physiotherapy (instrumental and appraisal needs), guidance on self-management (instrumental and appraisal needs), information and psychosocial support (emotional needs). Longer term needs, in contrast, centred upon the maintenance of health, the management of long-term sequelae and the secondary prevention of illness (informational and appraisal needs). These categories will guide our analysis in terms of whether, how, when and by whom these needs were met at identified stages in the recovery process. We will also explore experiences and perceptions of *unmet* need and examine their impact upon recovery.

#### Approach 2: a constructivist grounded theory approach

A priori categories such as those of the TIR framework do not exist in approaches such as grounded theory. This approach is characterised by the use of flexible analytical guidelines aimed at building inductive middle-range theory through successive processes of data analysis and theory development.<sup>63</sup> The steps involved in grounded theory are reiterative in nature and consist of the following: simultaneous collection and analysis of

data, a two or three stage coding process (from open coding at the beginning to focused coding as the analysis progresses, categorising data under emerging conceptual themes), constant comparison of incidences within and across the entire data set, memo writing (aimed at capturing conceptual analytical processes—audit trail), theoretical sampling and, finally, the integration of the themes into a theoretical framework which explains the data.<sup>64</sup> A *constructivist* grounded theory approach directs attention to the complexity of the world we live in by accounting for multiple perspectives on and interpretations of social phenomena (eg, recovery from critical illness) and recognising participants' active engagement in 'making sense' of their experiences.<sup>65</sup>

Data analysis will begin with open coding and progress to focused coding within and across data sets. Focused coding is the second major step in grounded theory analysis identifying common themes and thus shifting analysis to a higher conceptual level.<sup>64</sup> In order to capture change over time, we will summarise each interview and case before analysing change *across* cases to derive at a theoretical framework of recovery over time. Part of this process is the iterative adaptation of the interview guides, which will reflect the emerging themes and foci of analysis.

#### Qualitative Health Needs Assessment

We will subsequently use Qualitative Health Needs Assessment methodology<sup>66</sup> to identify the key attributes and preferences, as perceived by patients, for informal support and healthcare provision at key stages in the recovery process. With regard to evolving informational needs among patient groups, for example, the existing literature suggests that patients have a preference for face-to-face dialogue with clinicians, telephone follow-up or written information at subsequent stages in the recovery process.<sup>17 18</sup> Analysis will inform the development of a questionnaire-based instrument which will be used in a subsequent large-scale study of stated values and preferences for alternative models of service development among survivors and their family members.

#### Summary

Qualitative research among survivors of critical illness is comparatively rare, and longitudinal approaches are rarer still. This study is novel in that it incorporates both methodological and theoretical triangulation into its analytical strategy. Importantly, this strategy addresses the *empirical practice-related* concerns of health services researchers while enhancing its analytical or explanatory potential in terms of advancing our *theoretical* understandings of recovery.

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**Competing interests** None.

**Ethics approval** Ethical approval was provided by the Lothian Research Ethics Committee (10/S1101/45).

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